



always your child

A booklet by and for parents whose baby or young child
has died suddenly and unexpectedly.

sids^{and}**kids**

Sigmund Freud wrote to a friend after the death of his daughter, Sophie:

“Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute, no matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be...it is the only way of perpetuating that love which we do not want to relinquish.”

[Freud, S. (1929) Letter to Binswanger. In EL Freud (ed.)
Letters of Sigmund Freud, New York, Basic Books.]

Foreword

This volume provides guidance, support and wisdom for those who have lost a child. There is honest recognition of the grief and pain, and of the tragedy inherent in such loss. The words of others are both comforting and enabling – for they show that others too have grieved. There is a great humanity in this book in its acknowledgment of the enormous value of others' words in showing there is a pathway to survival, and that others have gone along this path.

There are descriptions of immediate and early responses; of the wide range of emotion, thoughts and horror; of the decisions that must be made. The early weeks and months and all that is inherent in these, the circumstances of different deaths and different settings, including those of violence, all impact. The words of the authors and especially the words of those who have been through such experiences, the impact on individuals, on family members and families as a unit, are all dealt with in sensitive and helpful ways.

This booklet can be a source of advice, a consolation, and a gentle guide to the future. The words it holds are those of the realities of such loss, and the ongoing life that must encompass this. I would most strongly recommend it.



Emeritus Professor Beverley Raphael

AM, MBBS, MD, FRANZCP, FASSA, FRCPsych

29 May 2000

Index

Introduction.....	5
Your child has died	
Straight after the death	7
What is grief?	
Initial reactions	
Shock & disbelief	
Anger	
Guilt	
Blame	
The first few days.....	16
Accepting help & support	
Alcohol & prescribed drugs	
Take your time	
The funeral	
First weeks & months.....	22
Particular circumstances.....	24
An only child	
A twin	
An adopted or foster child	
A child with a disability	
Murder or another crime	
Life support	
Impact on family members.....	32
Do men & women grieve differently?	
Effects of grief on your relationship	
Sex, pleasure & intimacy	
The single parent	



Impact on family members (continued)	
Helping your other children	
Fears for your other children	
Another child?	
When people ask...	
Grandparents' grief	
What can help?.....	43
Your network of family & friends	
Helpful people	
Insensitive comments	
Anniversaries & birthdays	
Creating memories	
You may take comfort in your beliefs	
Other bereaved parents	
Talking with a counsellor	
Changes over time	53
A changed outlook	
Remembering.....	55
Acknowledgments	59
Publications available from your local SIDS and Kids office.....	60
SIDS and Kids Organisations.....	Inside back cover



Introduction

This booklet shares the experience of parents who have had a baby or young child die suddenly and unexpectedly. The children have died from SIDS, sudden onset illnesses, motor vehicle accidents, home and other accidents, drowning or homicide.

Because of their experiences these parents understand some of your pain, and through this booklet they try to tell you what they thought, felt and did after their children died.

While the circumstances of your child's death are unique, the parents hope that by sharing their experiences they will help you, and those around you, understand what you are going through, both now and in the future.

“ Words are completely inadequate to describe what it feels like.” (Jenny)

Your child has died

This is an unbelievable and unacceptable tragedy.

The death of a child has been called the ‘ultimate tragedy’, and is probably the most devastating event that can happen to parents. It is perhaps the hardest thing you will ever have to face.

When a child dies, it is against the natural order of things. No-one expects to outlive their children. The natural expectations, hopes, dreams and aspirations you had for your child have been shattered.

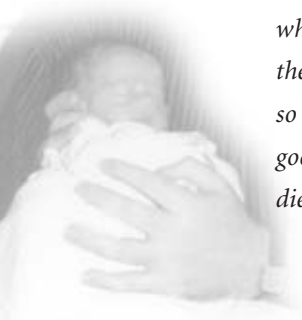
For many parents this could be the first time anyone close to you has died. You may feel shocked, overwhelmed and confused about what to do next.

“ It was so unexpected. It’s a part of you dying – literally. A child is of you and out of you, an extension of yourself, someone you naturally want to protect, to nurture. In recent years, both of my parents have died, a brother-in-law, and several friends, each death affecting me differently. The sudden death of my own child affected me like no other.” (Erica)

“ You know that people die when they get old but it does not enter your head that your baby or child is going to die. It’s such a shock. Also, with older people you have had a chance to express yourself to them. But with a child, you always believe that there will be a tomorrow. “ (Glenn)

“ All the expectations, the vision, the dreams and ambitions you had for your child disappear.” (Sue W)

“ I had a friend who had recently lost a grandparent and who felt that grief is only for the people left behind. With an elderly person who has lived a long life this may be true, but when a child dies you are grieving not only for the fact that you are doing without them, but also for the fact that they are doing without you. That they will never have the lifetime of experiences that others have. As my mum said “Samuel will never see a tree”...I think there was a time when it was not that unexpected for children to die. For example, at the turn of the century, people had larger families and many people would know families who had lost a child. Nowadays when a child dies, it is probably the first such experience within the community network around a family... That’s what makes it so enormously lonely. If you’ve had a parent die, then there’s a good chance that you’ve got friends who have also had a parent die, and so you have a bond there, and they can give you support



because they've been through it. But at the time of losing Samuel, we knew no-one who had lost a child and that compounded our feelings of aloneness. (Jenny)

Straight after the death

Because the death of your child has been sudden and unexpected, you may be experiencing the effects of trauma as well as profound grief. It is important for you and those around you to understand that although the feelings you are experiencing can be intense and even frightening, they are normal and natural expressions of your love and sense of loss. They are a natural reaction to the suddenness and enormity of this tragedy. Grief is a normal process; it is not a sign of mental or emotional instability.

Your life has suddenly been turned upside down. You may feel overwhelmed by the extremes of feeling and behaviour you are experiencing. You may feel you cannot bear the pain. You might wonder if you will survive. But it is our experience that you will.

What is grief?

Grief is the natural and normal response to the death of a loved one. It is the feelings which express your love for your child, and the pain you are experiencing following your child's death.

Grief is unique to each person. Everyone grieves in different ways. There is no right or wrong way to grieve. Nor is there a set timetable for grief - parents grieve for different lengths of time.

While no-one can tell you how or how long to grieve, there are elements of grief that are more or less common to everyone. It can be helpful to understand these common elements and to learn how others have dealt with them.

“ I read a lot on grief, personal stories of survival and different kinds of loss, some spiritual writing and professional grief and loss stuff. I take what works for me and leave the rest.” (Fiona)


“ I read everything I could get my hands on – particularly stories from other parents. These sad stories showed me that although I was consumed with loneliness, I was not alone in the grief for a child. Others like myself had walked the path before me, and they had survived the experience.” (Sue W)

Initial reactions

“ I thought I had totally lost my grip. Some of the things I said and did, I could not have been held responsible for. I did some really mad things. People told me later on of the things I said and did – I had no idea.” (Susan)

You may find, like a lot of people who have had this experience, that you feel like you are going crazy. You may have many or all of the following feelings: shock, disbelief, a sense of unreality, numbness, sadness, fear, anxiety, anger, guilt, emptiness, yearning, searching, hopelessness, helplessness, confusion, absentmindedness and loneliness.





Many parents feel that they just want to be with their child. This is a very common feeling, and although frightening to your loved ones, the parents whose stories appear in this booklet show that you can and will go on. However if these thoughts persist and continue to worry you or your family, it would be wise to consult your doctor or some other trusted health professional.

It is not uncommon to have flashbacks, strange and vivid dreams, visions of your child, reminders of past traumas, irritability, difficulty in relating to those close to you, physical pain, loss of appetite, nausea, sleep disturbances, restlessness, agitation and fatigue.

It is important for you to know that these feelings, thoughts and behaviours are all normal, and to be expected at this very difficult time.

Shock & disbelief

Straight after a sudden and unexpected death people are usually in shock for a while. It's hard to believe what has happened and everything seems confused and unreal.

“ My being fractured. One part stood there gaping in disbelief, another part looked on like a curious spectator while yet another part of me leapt into action doing what had to be done. Franklin’s death had me feeling I had sustained a fatal wound leaving me stunned and weak and utterly, horribly cold. The winter had been mild, but after Franklin died, the weather turned bitterly bleak.”

(Erica)

“ I didn’t know what my heart was doing. I didn’t know what my feelings were. I was in so much shock. It didn’t hit me until the day after the funeral that Phillip was actually dead. I had no idea of what was going on. The funeral arrangements went straight over me – it just didn’t sink in. So in that way I relinquished so much of what I would’ve changed because I was in this daze.” (Susan)

“ When my son Jack died I wanted to be with him. I’d come home from work, I’d carried him into the ambulance. We went to the children’s hospital. I did not want to go home. I needed to talk to him. I had not told him what I had planned for his life. We walked out onto the street and we were in a daze. I went home and said I just wanted to be with him.” (Glenn)

“ I waited for someone to come to the door with Henry and tell me that a mistake had been made.” (Sue W)

“ The staff at the children’s hospital had been very gentle and discreet. They let us spend as much time with Franklin as we wished. Yet the time came to leave him behind and to come home without him. I don’t know how we got through that night or the next day.” (Erica)

Anger

Anger is a common and normal reaction. It’s OK to be angry when your child has died. It’s unfair and unjust. You may be angry at life, fate, God, another person, health professionals, yourself, or even at your child for leaving you.



“ Anger is a really natural response, a healthy response, a natural energy in the face of what has happened, no matter how your child died.” (Fiona)

“ I was angry. Angry it was me, angry it was my life, angry it was Henry. I felt cheated.” (Sue W)

“ I’ve always been emotional anyway, but after Lewis died the anger at the injustice would build up in me to a point where I would just scream and scream until I was hoarse – and then the tears would come.” (Kath)

“ At first I felt angry and frustrated. . .It’s still a bit of a blur, but some things I can remember very vividly. I could’ve smashed walls – I felt like that. I remember the days afterwards. I raked the front lawn until there wasn’t one leaf on the ground. I just didn’t know how to be. . .I don’t think I stayed angry for very long. But the emptiness stayed with me for a long time.” (Peter J)

“ I found that the anger came about a month down the track. I was really, really angry. Not only because Phillip had done it to me; how dare he leave me; how dare he ruin my life; how dare he show me what real grief is. He has ruined my life forever. I will never be the same person again. I will never think the same way. He’d affected all these friends and family of mine. What right did he have to do this?” (Susan)

You may be asking: Why? Why my child? Why the injustice?
Why so young? Why me? Why us?

“ I was jealous and envious. I can remember feeling ‘hard-done-by’. Here are all these people with new babies, and I’ve been left in this hell hole.” (Lesley)

“ I couldn’t help but think it should have been so different. I felt cheated. I watched as other babies were pushed around in prams, or parents playing with their children in a park. I feel that I have missed out, that my son has missed out.” (Sue W)

Anger is another way of expressing pain and like other feelings it needs to be acknowledged. Many people benefit from talking or writing about their anger. Anger should be expressed, but it is best directed at objects rather than at people. You may find that physical activity is helpful - gardening, chopping wood, walking, running, swimming, even punching a punching bag, may provide you with an outlet for your anger.

“ James was murdered. For me, it is important to use anger, rather than let it boss me around or consume me. I have ranted and raved with a couple of friends I felt safe with. I wrote the letters one never sends, read them out and then burnt some of them. Other letters I read with a friend present, cried and screamed and thumped a cushion. It was good to do it with a friend who was affirming and could keep their stuff for others. I smashed plates from St Vinnies in holes Jack dug in the garden with brick in the bottom so I got a ‘SMASH’ rather than a ‘thud’. I cursed and swore and laughed that deep black laugh of grief. I then gathered up dog poo from the garden and chucked that in as well and then...I planted some trees in the holes. The anger meant I was alive... There was movement, I had no idea if it was forward, I couldn’t see the road ahead. My lifeforce was pulsating - claiming

my life back. Naming and moving the outrage was a step. The anger meant I was healing.” (Fiona)

Expressing anger may make you feel a little better. If anger seems out of control for an extended period of time, or is affecting your relationships, it might help to talk to someone you trust. This might be a family member or friend, another bereaved parent, a counsellor, your G.P. or another professional person.

Guilt

As parents, we believe we must protect our children at all times, so that when a child dies, it feels like the ultimate failure. You may feel you have let your child down and are no longer a good parent. You may feel you have not lived up to your responsibilities. Guilt is an inevitable, common and normal reaction to such a tragedy.

Many parents are tortured by ‘if only’s’ and ‘what if’s’. You may blame yourself for something you did or did not do that may have contributed to the death. You may feel you have failed to protect your child.

If you are blaming yourself for your child’s death, you may need reassurance that you would not intentionally have harmed your child. Over time you realise that you did your best. No matter what happened, you did the best you could have done under the particular circumstances.

“ The thing that I see different about a child dying is that you feel more acute guilt...As a mother, I was responsible for his well being and I ask myself what could I have done to change the outcome.” (Wendy)

“ When Rachel died, one of the thoughts that went through my mind was how could we tell our parents such a terrible thing had happened. As a parent you feel so guilty. We also felt we’d let all our family and friends down.” (Leeanne)

“ We lost our son in a home accident. I felt like an alien walking up the street in our small community for a long time. I felt as if everyone ‘knew’ but I was scared they didn’t know the real truth of how something like this could happen...I desperately wanted another baby, straight away, but when I fell pregnant I was tortured with thoughts of not deserving another baby. (Kath)

“ I felt as if everyone who looked at me knew what had happened. I tried not to look people in the eye. I felt so ashamed of myself.” (Darren)

“ I will always blame myself for Danny’s death. I remember saying, especially in the first few days, “I killed Danny” over and over, and everyone kept saying “Don’t say that – it was an accident”. But one sweet sister-in-law said to me “It’s OK to say that”. She was the only one who knew I had to say it over and over to hopefully get it out of my system. Now 71/2 months later she still comes at least once a week and is my favourite visitor.” (Peter M)

If you feel guilty, talk about it, write it down, or express it in some other way until you can let it go, at least a little. Being prevented from expressing your guilt is not helpful. Find someone who won’t say “Now come on, you shouldn’t blame yourself”. Find someone who is able to really hear without judgment, your thoughts, feelings, doubts and fears.



Blame

Blame can arise in different ways. It may occur when your partner or someone else is caring for your child at the time of the death. This might be a relative, friend, baby sitter, day care centre or hospital staff member, or some other person. You may find yourself blaming them, or even yourself for leaving your child in their care.

Try not to accuse anyone unjustly, (unless you know that deliberate harm was intended, or another crime was committed – see page 24)

In the case of a tragic accident, for example, accusations of blame are devastating. Almost certainly the other person will be feeling profound regret, guilt, sadness, and possibly even fear. They, too, need support from those close to them.

On the other hand, try not to let your feelings smoulder without being expressed. Instead start talking about what you are thinking and feeling with another trusted person.

“ Blame is difficult. At some time or another it feels better to blame others for what has happened. My daughter Jessica was born with a disability and spent many times in hospital, usually for the same illness. Throughout we were taught what to look for and how to start treatment at home. The last time she was sick, we didn't pick it up. I blamed myself for not getting to the doctor earlier and have also blamed the doctors and nurses because I thought they weren't quick enough with treatment. Now that I stop and think, everyone has been blamed by me for something. I have come to realise that it's not anyone's fault, least of all my own, and this is part of grieving.” (Karen)

The first few days

“ It’s difficult to remember the days between death and burial. We were still in shock, nevertheless greeting visitors and arranging things. I do remember one friend coming up from town to visit me saying how surprised she was to see me looking normal. If only she could have seen how I felt. I’ve learnt that grief is very personal and quite internal. Nowadays we don’t have any signs to show we are bereaved. There are no special garments, nor rituals (apart from the funeral) nor time to acknowledge our losses. Our whole world may have caved in but we’re not to skip a beat! This made me so angry. I wanted to scream so that the whole world would stop to notice, just for a second.” (Erica)

“ In those first few days the thing that really annoyed me was that the world is still going as fast. Cars are still honking their horns on the road because they wanted to go that bit faster. And the world did not stop. I felt that the world should have stopped for me.”
(Narelle)

Accepting help & support

Most parents feel that the greatest help they receive is the care and support given to them by their family and friends. One of the best things you can do at this difficult time will be to accept the help and support offered by those closest to you. Try not to shut them out. They will most probably want to support you in any way they can, even if they don’t know what to say or do. You may need practical help such as in preparing meals, washing, shopping or support with your other children. Don’t be afraid to ask for, and accept others’ help.



We all need the help and support of other people at some time in our lives – you will be able to help someone else at another time. It is your turn now to have support.

“ It is not long before you realise that your family and friends are there to support and comfort you. It’s not always the words they say, sometimes it’s their actions and the fact of just being there that makes a difference.” (Darren)

“ The level of support we got from family, friends and the local community, while James was missing and after we found out he was dead, was amazing. The house was always full of people, talking, organising things, and heaps of cooking, eating and washing up. Fiona and I had to make times to withdraw and leave people to look after themselves. One thing we did was to ask some of our closest friends to be responsible for specific tasks, including fielding phone calls and visitors. The phone was ringing all the time with messages of support and condolences. We couldn’t talk to everyone who rang but it was great just to read messages that were taken down and hear that people had called and were thinking of us.” (Jack)

“ I personally find accepting help from people difficult at the best of times, but accepting help when Saffron died just seemed to happen. I think it was because I was feeling totally unable to function, it just made sense for other people to take over for a while.” (Lisa M)

“ The support for our family after we lost Braddon was so overwhelming. Letters from his little class friends and their parents, phone calls, cards, flowers and letters from friends talking about what they’ll always remember about him and what they’ll

miss. Braddon touched so many people's hearts and I felt so proud of him and so sad at the same time. I was never left alone after I lost him and I was so grateful because I never even had to ask. I was petrified of being alone."

(Lisa P)

" I remember the night – was it two days, three days or maybe even four days after Molly had gone. Without invitations, six or so friends and mates came around. The beer they brought gave us all an excuse! The talk was basic - work, football and eventually family. This was one of the most important events to happen, at a time when I found it so difficult to express my feelings and my grief.

I was the husband, the father to two of Molly's brothers, I had to be strong, I had to control my feelings, I had to show everyone I could handle this in a 'manly' way. I thought Jill needed me to be strong too!! I remember how we all hugged and embraced each other. There wasn't a dry eye to be found. They all knew I was hurting. And I knew they cared. Our friendships go on." (Ian)

Often friends and family don't know what to say or do.

A booklet entitled *"To family and friends – You can make a difference."* is available from the SIDS organisation in your state or territory.

Alcohol & prescribed drugs

It is recommended that parents don't drink a lot of alcohol or use tranquillisers or similar medications because they only delay grieving. The use of alcohol and medications can result in you having a reduced capacity to play an active role in funeral plans and

you may later regret that you were not more aware of events in the days immediately after the death of your child.

“ Our bodies can serve us well. I have made sure I looked after it. I wanted to stay present no matter how scary, painful or shocking.”
(Fiona)

Take your time

If you are reading this booklet before the funeral, the most important thing to keep in mind is to take your time and make decisions which are right for you. There is no need to rush anything. Most parents and other family members find it helpful in the long term to have spent time with the child who has died, saying and doing whatever they feel they need to.

“ The funeral director said we could bring Samuel home. We held him at home for a while, we walked around the garden with him, we sat in the sand-pit and said “This is where you would have played”. The funeral director took him back to the funeral parlour, prior to the funeral the next day. We did what we wanted to do.”
(Jenny)

“ It was an amazing comfort for all of us to have Danny home with us.” (Peter M)

“ The funeral director came and we cobbled together a funeral. Still in deep shock we did our best. This was our first family funeral and I just could not believe that it was our little Frankie that we were arranging to bury. The funeral director tried to be helpful. We arranged a viewing at the parlour beforehand. I’m so glad we did because we were able to see that Franklin was quite dead. In

fact he didn't look like I remembered him. I was shocked by the chill when I touched his face. His spirit had certainly gone and somehow this made it easier to bury him the following day."

(Erica)

" I didn't think you could have a funeral on the weekend but the funeral director advised us that it was best not to rush things. This was going to be the last thing we would do for our little man and it should be the very best we could manage. We didn't want Lewis waiting at the church by himself, so the funeral directors arranged a car big enough to bring him home first and pick us up so we could all go together as a family. Our house teemed with people all week between when Lewis died and his funeral. We asked everyone to leave us alone on the day. My husband, our four year old son and myself had some time to ourselves in a calm atmosphere, almost serene. When the funeral directors arrived, with Lewis, to take us to the church, we were united and as prepared as was possible.: (Kath)

The funeral

Well-meaning family and friends sometimes think that by giving you advice or even taking over the funeral arrangements they are helping you. However, it is a good idea if you are able to have as much involvement in the funeral arrangements as you can. It is your child who has died and it is important that in planning the funeral you are able to express the loving relationship you had with your child in a way that is meaningful for you.

“ You look to people for advice and hope that you will hear only helpful advice. You are glad when someone says they will take care of something for you in the way you want it done. Unfortunately much of the advice, expectations of friends and family have evolved from experiences with the death of an aged person. Much of this advice is not necessarily applicable to the death and funeral arrangements of a child.” (Jenny)

“ Julian was born with a disability. I felt I was OK during those first days after he died. There was a job to be done and it had to be done in the best possible way we knew how. There could be no regrets, and there was no one else to do it. This was to be our goodbye to our beloved son and it had to be great. It felt as if the whole of Julian’s life had come together on this day and we had only one chance to get it right. It was the most difficult job we ever had to do, but I am glad we did it the way we thought Julian would have chosen it.” (Thereese)

“ It was important to take time to plan the funeral. We had special songs played, and we asked family and friends to write down their memories of Tessa. These were read at the funeral. I often listen to the tape of the service and feel so proud of the way Tessa touched so many people. The funeral was a celebration of her life.” (Debbie)

You may find it helpful to read *“Choices in arranging a child’s funeral”* which was written by parents, and is available from the SIDS organisation in your state or territory.

First weeks & months

In the first weeks and months your grief may take up every moment of the day. It might feel as if it has taken over all aspects of your life, affecting you emotionally, physically, intellectually and spiritually. You may ask yourself and others, “How long will this pain last?”

Sometimes you might feel you are ‘taking one step forward and two steps back’. You may even wonder if you will survive.

“ Six months is not far down the track. It’s just so difficult every day. I still think Tara is on holiday and will be coming back. Someone asked me this morning how I was and I said “OK”. But half an hour later I walked past a photograph and I was bawling. The pain in my heart will not go. There is a big hole and that is the pain.” (Narelle)

“ While we still lived in the same house that Lewis had spent all of his short life, I never once walked past his room without looking into his cot, just to check that the whole thing had not been just a nightmare. I’m a natural organiser, I like to plan for every contingency and know that I’ll be in control of our lives. Yet suddenly and unexpectedly here was something utterly beyond comprehension, let alone control. I felt so helpless that there was nothing I could do to change it.” (Kath)

“ When Sam died, all I wanted to know was that I could survive. I wanted the hope that I could survive.” (Wendy)



“ Within the first few weeks I needed to know that there was a tomorrow, I needed to believe that the incredible pain would go away. I guess I wanted to be ‘normal’ just like before. I wondered how long I could possibly endure such pain. I needed to know how others coped. I needed to know it was possible. I quickly learned that there was no recipe to get through. I had to find my own way of dealing with all of my new emotions and fears.” (Sue W)

“ I read lots of books about grief, and one picks up this general expectation that there is a linear process one goes through and then is ‘over it’ (a dreadful concept). For a while I worried that it didn’t seem to be getting any easier. A psychologist explained to me that the subconscious is very protective. Initially one goes into shock with a kind of numbness and un-reality (in which it is often possible to do amazing things and appear very in control). Later some of this numbness wears off and the really intense feelings surface as one is capable of dealing with them. So, what I initially perceived as being ‘stuck’ was, in fact, a good sign that I was gradually dealing with things as my subconscious dealt them up to me when I was ready to be able to cope with them.” (Jack)

Particular circumstances

An only child

When an only child dies, parents may feel that they have lost their identity as a family. However, while your parenting 'role' is gone, you will never stop being a parent. Your child will always be a part of your family.

“ I felt robbed of my identity. When Phillip was alive I was a mum, and I was doing all right thank you very much. Next minute, I was nobody. I had no son. I wasn't a mother any more, and here are all my friends with their nice, perfect babies having a nice time. I found that really hard.” (Susan)

A twin

The death of a twin is always a tragedy, and it is not lessened because you happen to have another baby of the same age. Not only are you grieving over the death of your child; you've lost that 'specialness' that goes with having twins, and you may worry about the effect of the child's death on the twin.

“ The greatest day of my life was when I had twins. Stephanie and Natalie had a special bond between them. The day Stephanie died we came home, and seeing Natalie standing at her sister's cot looking for her was heartbreaking. I cry because I know Natalie will never get to grow up with her sister - never get to have that bond that twins have. It's hard because you are constantly reminded of a lot of things, because you have one twin here and one is not. It helps when you talk to someone who has been through what you have been through.” (Bridget)



“ When Saffron died, a part of me died as well. The pain was so intense it felt like someone was ripping my heart from my body. I have never felt such emotional and physical pain. I didn’t want to continue in life but I had too. I still had Elliott who needed me for his own survival. It was really confusing. I was grieving for my baby Saffron while I was caring for my baby Elliott. I still struggle with this issue 16 months later and probably always will.” (Lisa M)

“ We had spent nine months trying to work out how we were going to cope with two babies and congratulating ourselves on how clever we were to have the ‘perfect family’ (boy and girl) as our first children. When Tahlia died we were left in a state of shock and disbelief. How could Luke be so perfect and healthy and Tahlia dead? How can you celebrate and bond with your new son and grieve for your daughter at the same time?” (Chris)

An adopted or foster child

There are special issues for families when an adopted child dies. Adoptive parents have gone through a lot to get their child. If you are an adoptive parent you have probably endured the grief associated with infertility, and the long process of assessment, approval and placement. The grief associated with the death of your adopted child can be compounded when others don’t acknowledge that the child was indeed your child.


Foster parents may also find that their grief is not fully acknowledged or understood by others.

“ James was our adoptive child. James had been with us for a year when he was murdered. However bureaucratic processes being what they are, the adoption had not been formalised and we were in a bit of limbo as to whether we were legally his parents, which caused some problems. But the reality was we were his parents. We were the ones who had to face the media and appeal for information when he was missing – the hardest thing I have done in my life. We were the only people who could organise a funeral that appropriately reflected the wonder and beauty of his life... There was always something very special about the way James came into our lives and I believe the drawn out process of approval and placement meant that we never took him for granted. We lived life to the full with him because of this, and I will be eternally grateful for this because even though his life was so short, I have no regrets about anything we did.” (Jack)

A child with a disability

If your child had special needs, you probably devoted a great deal of your time to caring for him or her. You may find that you can't even begin to imagine how you will fill the hours you previously devoted to your child.

“ Our daughter Stephanie was born with Charge Syndrome. When she died we thought, “How could this happen?”. We had her for thirteen months. She'd been in and out of hospital. Stephanie had multiple problems. I felt like maybe I didn't do enough for her, why did she have to go, I didn't deserve this – she was my child. Then I thought, “How could I be selfish?”. Stephanie fought for thirteen months of her life, never really complained and was always happy.



I am thankful because I got to have that special time with my daughter.” (Bridget)

“ When Julian was born we embraced a life on an emotional rollercoaster of which one day was never even similar to the next. It was a life of chaos, beautiful chaos, not even similar to anyone else we knew, but we loved this life. A day never went by when I was not thankful for Julian and I openly felt that I was wrong because I never wished him to be any different than he was. We were thankful for what it gave to our other children and ourselves and we believed that this was how it would be for the rest of our lives. This was our purpose. I was so proud of Julian. He spoke through his lack of words and his inability to walk, and the understanding and patience that he demanded from others. Then so suddenly and unexpectedly he died. The pain was so great. The thought of the emptiness from the minute we woke until we slept was unthinkable. From that day on life would once again change and a bitter calm filled the air and we knew that life would now be easier but never ever better. I felt that we had lost what made us special, privileged and unique.” (Therese)

Murder or another crime

Although some other deaths, including many accidents, can be violent, a murder is unique because it is intentional. If your child was murdered, not only will you be experiencing the thoughts and feelings other bereaved parents go through, you will most probably experience intense anger and rage at the perpetrator, including thoughts of revenge, and possibly a preoccupation with thoughts of your child being terrified and unprotected.

Also, if your child died violently through murder or another crime, you will probably find yourself having the added stress of dealing with police investigations, the media, lawyers, trials and other aspects of what may seem to be an impersonal or even unjust criminal justice system. These legal processes will almost always take some time.

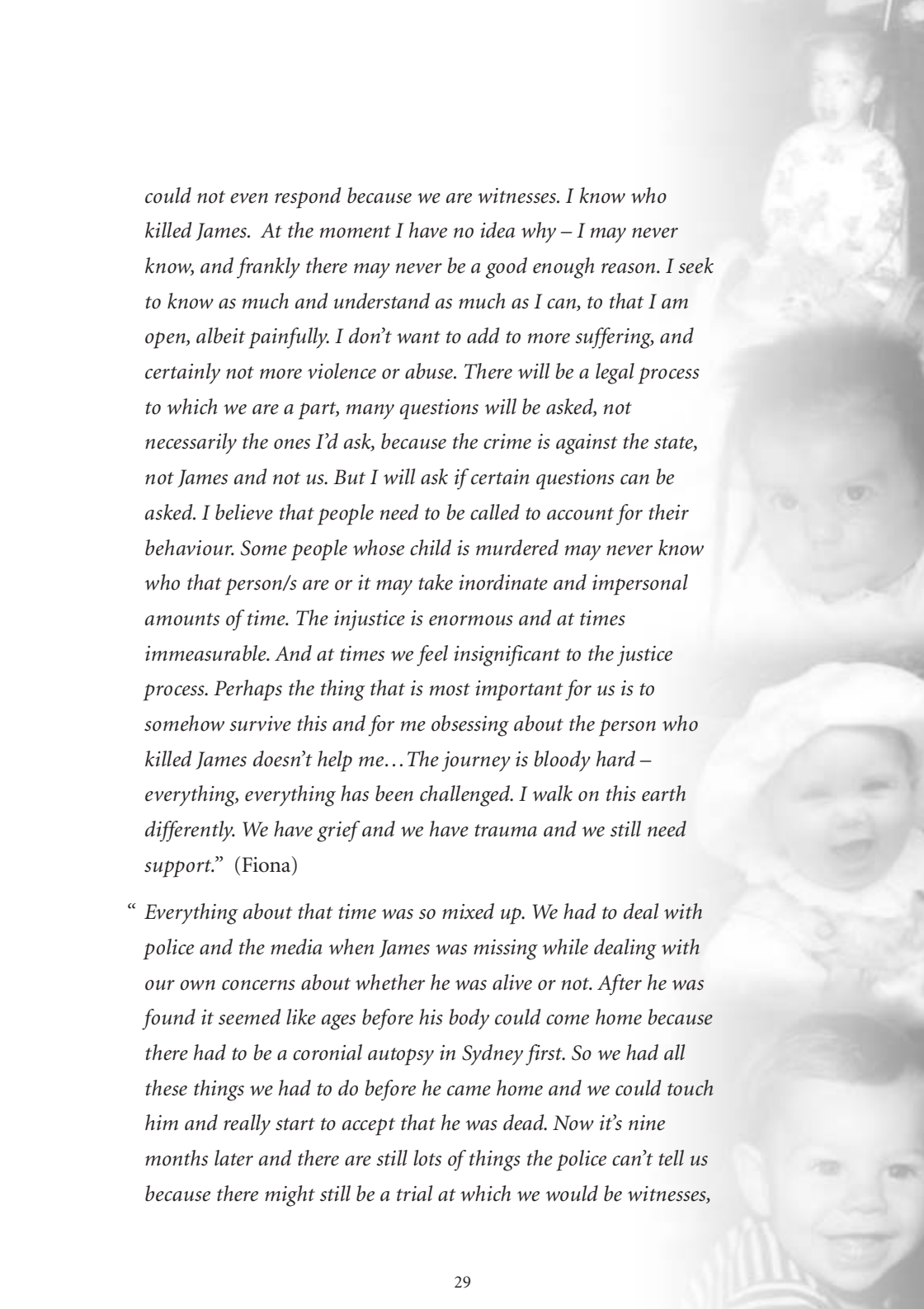
If your child's killer is not found, or many of the facts surrounding your child's death are unknown, you will justifiably feel that nothing feels finished and that justice has not been served.

You will probably find that these unique complications keep the wounds open for longer than other parents, and it is crucial that you find good support, and someone you can really talk to.

“ Murder is so hard to comprehend. I don't believe I will ever be able to comprehend it...I always made sure I was there for Braddon through every step of his life, but I wasn't there when he left. It's such a helpless and overwhelming sadness... Braddon's innocence tears at me. He has suffered the cruelest betrayal and lost the life he loved. My anger and sadness are immeasurable.”

(Lisa P)

“ Murder is OUTRAGEOUS. It is unacceptable. There is no excuse. It is so shattering – so impossible to comprehend. I felt the English language failed miserably in helping me, or giving me the words to talk about how I felt, or what was happening to and for me. James' death affected thousands of people, but we are his mum and dad, and we had a different journey of police interviews, information not available to us because we were witnesses (not to his murder but his abduction) dealing with the media and dealing with sudden and distressing information from the media to which we



could not even respond because we are witnesses. I know who killed James. At the moment I have no idea why – I may never know, and frankly there may never be a good enough reason. I seek to know as much and understand as much as I can, to that I am open, albeit painfully. I don't want to add to more suffering, and certainly not more violence or abuse. There will be a legal process to which we are a part, many questions will be asked, not necessarily the ones I'd ask, because the crime is against the state, not James and not us. But I will ask if certain questions can be asked. I believe that people need to be called to account for their behaviour. Some people whose child is murdered may never know who that person/s are or it may take inordinate and impersonal amounts of time. The injustice is enormous and at times immeasurable. And at times we feel insignificant to the justice process. Perhaps the thing that is most important for us is to somehow survive this and for me obsessing about the person who killed James doesn't help me... The journey is bloody hard – everything, everything has been challenged. I walk on this earth differently. We have grief and we have trauma and we still need support.” (Fiona)

“ Everything about that time was so mixed up. We had to deal with police and the media when James was missing while dealing with our own concerns about whether he was alive or not. After he was found it seemed like ages before his body could come home because there had to be a coronial autopsy in Sydney first. So we had all these things we had to do before he came home and we could touch him and really start to accept that he was dead. Now it's nine months later and there are still lots of things the police can't tell us because there might still be a trial at which we would be witnesses,

and that could still be a year away. At one level we had to realise that the legal system is a world unto itself and it's not about a process that helps us understand or deal with what happened to James. The important processes for us have been the ones we had control over, the memorial service by Daylesford Lake the day after we found out he was dead, his funeral, what we did on his second birthday. The legal processes are still there, they have to be dealt with and they may be important to us in getting some information that helps us understand what happened and why, but we had to learn not to see them as the resolution of our grief.” (Jack)

Life support

The decision to turn off life support is probably one of the hardest decisions anyone ever has to make.

“ We rode the roller coaster where they would say Henry was going to make it and then no, he wasn't going to make it. I watched my child die. I gave the nod to turn off the life support. That is a trauma in itself.” (Sue W)

“ My head told me that giving permission to withdraw treatment was the best thing for Hemani but my heart still tells me it wasn't the right thing for me. I wanted my daughter in any condition. Understanding and accepting this selfishness has been very hard.” (Megan)

“ My husband and I went through months of wondering whether we did the right thing in giving permission to withdraw life support. But, I feel our little girl is at peace and that she's God's little angel for all to see.” (Bridget)



“ Our daughter was born with Muscular Dystrophy. My feeling about turning off life support is that we could have kept our daughter alive with machines, but this was not her. Jessica helped us with this decision. She was never happy doing nothing, her eyes told me she had had enough. She is in God’s care now, doing things she could never do here and I know she is at her happiest now. Although 18 months later the thought can still cross my mind – “Did we really do the right thing?” (Karen)

“ The decision to turn the life support off was easy, hard and heart rending. The easy part sounds heartless but a parent does everything and anything to save their precious baby from pain and suffering. I don’t recall if I nodded or spoke out loud, but somehow the doctors knew that I wouldn’t let Ethan suffer any longer than necessary. I feel comforted knowing that my son is no longer in pain. I feel at peace knowing that my son will never suffer. I am pleased that Ethan and I were surrounded by family and friends; and I am honoured that Ethan chose to die in my arms and not alone.” (Tracy)

Impact on family members

Do men & women grieve differently?

Men and women typically express their grief differently, however it would be a mistake to say that all men express their grief in one way and all women in another.

When a child dies, it is generally understood and accepted that mothers will grieve. But it is not as widely accepted that fathers will grieve too. They will be deeply hurt, though some may not show their grief as openly as do mothers. Women are often more able to express feelings, cry, talk, share thoughts, and accept help; whereas many (but not all) men may speak very little about how they feel. Men often see themselves as needing to be strong, to be the providers, protectors, and problem solvers. Some are comfortable discussing their grief whilst others are not. They may find an outlet in physical activity and practical tasks rather than in talking, and may wish to spend time alone. This is common and not unusual.

“ Women have that advantage in that they tend to be able to approach one another. They are supportive. They are mothers. But for men it is different. I felt that if my wife and I both grieve, if we both bawl our eyes out, who is going to pay the bills? My wife has to grieve and I have to go back to work...I cannot take time out to cry for a week or two weeks. It's that male thing of being the provider.” (Glenn)

“ We were all very affected as a family, yet most of the support was directed towards me the mother...My husband grieved in his own private way and shared very little with me. I don't think he shared any of his grief with anyone.” (Erica)



“ Fathers hurt just as much as mothers...and when people say “And how is your wife?”, fathers think “What about me?” The support is lop-sided.” (Glenn)

“ Men aren’t very intimate with each other when they’re growing up as young men. A lot of their emotions are conveyed in physicality, so to get a man to talk about it...the immediate reaction is to choke it out. It’s like trying to wring something out of a dry sponge.” (Anthony)

“ I remember at times being in the staff room and someone’s said something to me and it’s set me off, and I’ve bawled my eyes out. I’m not embarrassed if I cry.” (Peter J)

The effects of grief on your relationship

The death of your child is such a major crisis, you and your family relationships will inevitably be changed. Each person grieves in their own way and in their own time, and when partners grieve differently it is important to understand and accept this. Just as you may not understand your partner’s ways, he or she may not understand yours.

After the death of a child, both parents are overwhelmed with grief, so neither may have the strength to support the other. This can make sharing feelings difficult. If this happens, try to find a friend or relative who has time to listen and support you. You might encourage your partner to also speak with someone he or she trusts, until the two of you are able to share your feelings with each other.

Fortunately, partners are often the greatest comfort to each other. Those couples who can share their thoughts and feelings and support each other, find this shared loss brings them closer together, making it a little easier to bear.

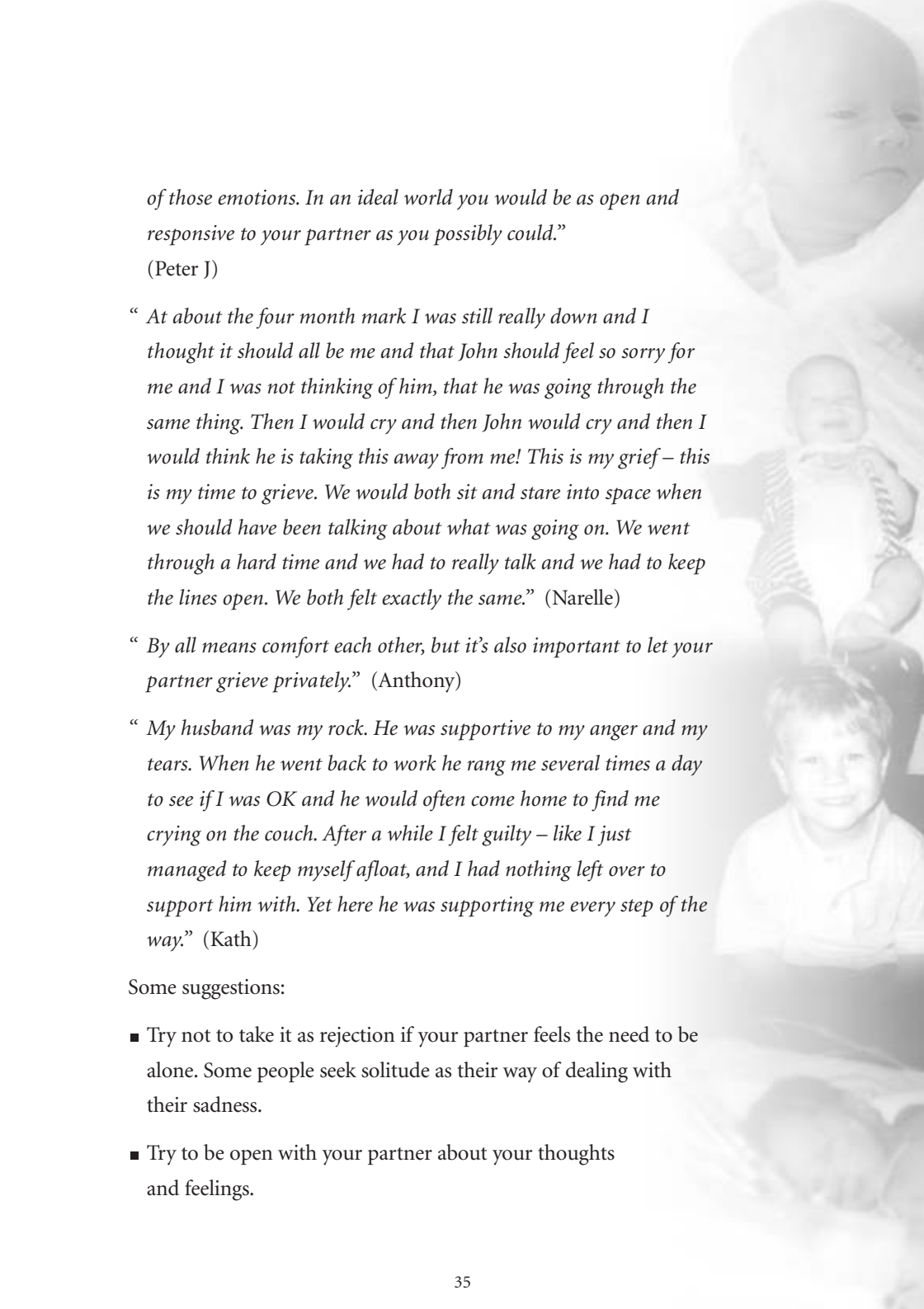
“ I was leaning so heavily on Anthony. It took me time to realise that he was in pain too. It may sound selfish, but it took time before I realised that he needed my support as well.” (Sue W)

“ I was the opposite. I knew Andrew was hurting just as much as I was. So I tried really hard to be ‘good’, so as not to upset him. Never actually did the two of us ever cry together. The whole time we were trying to help each other. I couldn’t bear the thought of us weeping together...I think we were almost wrong not to have a really good weep together. We were constantly trying to be brave in front of each other. When the tears came we would go off to another room. We would both do it. I don’t know whether it’s a good or bad thing, but I think it probably would’ve been better if we’d cried a bit together.” (Susan)

“ Unlike when a parent dies, for a couple, both parents are grieving – there is no stronger one. There’s no strength in either.” (Jenny)

“ I think it is really important to keep communication going. People grieve differently and you are so consumed with your own grief that you have not got much to give to anybody else. It is really easy to take exception and misconstrue your partner’s reactions.”
(Wendy)

“ It’s so hard at times to be compassionate to your partner’s needs. You might have just gone through hours when you felt so low and you might be coming out of it a bit and then it is your partner’s turn and it is so hard to be dragged back into it. It is the meshing



of those emotions. In an ideal world you would be as open and responsive to your partner as you possibly could.”

(Peter J)

“ *At about the four month mark I was still really down and I thought it should all be me and that John should feel so sorry for me and I was not thinking of him, that he was going through the same thing. Then I would cry and then John would cry and then I would think he is taking this away from me! This is my grief – this is my time to grieve. We would both sit and stare into space when we should have been talking about what was going on. We went through a hard time and we had to really talk and we had to keep the lines open. We both felt exactly the same.”* (Narelle)

“ *By all means comfort each other, but it’s also important to let your partner grieve privately.”* (Anthony)

“ *My husband was my rock. He was supportive to my anger and my tears. When he went back to work he rang me several times a day to see if I was OK and he would often come home to find me crying on the couch. After a while I felt guilty – like I just managed to keep myself afloat, and I had nothing left over to support him with. Yet here he was supporting me every step of the way.”* (Kath)

Some suggestions:

- Try not to take it as rejection if your partner feels the need to be alone. Some people seek solitude as their way of dealing with their sadness.
- Try to be open with your partner about your thoughts and feelings.

- Sometimes a look, a tear, or a touch may say more than words ever could.
- Above all, try to accept how each other feels and that each may have different needs.
- At times you may feel that your relationship will not survive this tragedy. However most couples do remain together. Understanding and supporting each other will help you to come through this very difficult time together.

Sex, pleasure & intimacy

For many grieving couples there is a change in sexual feeling and responsiveness. For some partners, sexual feelings may disappear altogether for a time, while for others these feelings may be intensified. Neither response is right or wrong, just different. If you are able to be patient with each other and talk about these feelings, you will probably find that the intimacy in your relationship will return to normal in time.

“ Within 24 hours of Molly Rose dying, Ian and I knew that we had to have another child to love and watch grow. We couldn't live in the darkness that surrounded us. We had to hold onto some form of hope. Although we remained bound by our sorrow and cuddled together in our pain I found it difficult to make love. How could I enjoy sex, when we had been making love the same night that Molly Rose died? Did she die alone in her bed whilst we happily enjoyed each other? It became a slow road of understanding, finding each other. Of touching and learning to give oneself again. If we had not wanted another baby so desperately maybe



physically our love might have been scalded. We worked together, and are moving forward together. I thank my husband for his love and patience.” (Jill)

The single parent

If you are a single parent you may face extra difficulties after the death of your child. If you have no regular partner to share your grief with, you might experience an overwhelming sense of isolation, loneliness and despair.

“ ‘Loneliness’ sums it up. Don’t get me wrong; I have a lot of support both from family and friends without which I’m sure I would not have made it. But it took two people to create Martin. Only one other person could feel that deep parental feeling as I do and the loss that I do and he is not here. We cannot comfort each other. I suffer my grief alone.” (Adele)

“ Society sometimes judges single parents harshly without any knowledge of individual backgrounds. I think sole parents have a special closeness with their children. I left Braddon’s father when Braddon was eight months old. I was a single parent to him for five irreplaceable years. Braddon was my only child. He was more to me than my son. We were friends, companions, a team. He was my love, my purpose, my life. I adored him. I had a male friend just before and after I lost Braddon. I broke the relationship off as I felt I was a burden to him and I couldn’t grieve the way I wanted to. Through the trial I liked and needed time to myself where I didn’t have to think of anyone else. I preferred it that way. I needed it that way.” (Lisa P)

Try to find a particular person that you feel comfortable talking with. This may be a family member, a friend, another bereaved parent, or a counsellor.

Helping your other children

Your surviving children will be deeply affected by the death of their brother or sister. Within reason, and depending on their age, try to share as many facts as possible surrounding their brother's or sister's death and involve them as much as you are able from the outset. They need information and choices.

Even if your children are very young, they will sense your feelings, and will probably worry about you. Don't be afraid to name your feelings – this can help them to understand their own emotions. Play, drawing, writing and reading together provide opportunities for your children to talk about their brother or sister, to ask questions and to express their feelings.

“ Involve your children in everything. They have some great ideas and you make them feel wanted by allowing them to have input into the funeral, cemetery visits and so on.” (Peter M)

“ There was a whole different culture in the house after Danielle died. Everything was different – bed time routines were gone, meal times were changed. We needed to take control and re-establish routine.

It was hard. We went away for two weeks. We needed to get our other two children ‘back’. No-one dropped in for coffee, the phone didn't ring. Nick and Steph had our undivided attention. Nick was such a different child after that.” (Melissa)



Your local SIDS organisation can give you ideas on how to help your other children.

Fears for your other children

After the sudden and unexpected death of your child you may feel that nothing seems safe and secure anymore. You may be fearful that something will happen to your surviving, and subsequent children. This is a common and normal experience for parents who have had a child die.

“ I’m so protective of our other daughter. I wake once or twice a night to go and check she is all right. No matter what she does, I always seem to think of the worst thing happening to her.”
(Leeanne)

“ I became obsessive about my other children’s safety, day and night. If such a thing could happen to a child who was cherished and cared for, why then anything is possible. If any one caught so much as a sniffle I would steel myself for another catastrophe. This went on for a long time. It left me feeling very low in self-confidence. It took ages to build it up again.” (Erica)

Another child?

Your child has died but the love you have for him or her is precious and enduring and he or she will always be a part of your family. In thinking about whether to have another baby, you may be afraid that you are being disloyal or that you may come to love that precious child less, but this will not happen. Every child is unique

and special and your love and memories will always remain – another baby will not diminish this in any way. You will not ‘replace’ your child.


The decision to have another baby is a very personal one, and only you and your partner know what is right for you, so trust your feelings.

“ I still feel my heart will never heal. I still miss Paris terribly but I have moved on since I have had another baby. Having another baby helps you to put your child’s death second instead of first. I love my baby Seth, but I wish so much that Paris could be here to see him.” (Elaine)

“ I knew another baby could not replace Molly Rose. I just needed another babe to hold, to smell and to touch. Then why was I so upset when the ultrasound/amniocentesis stated that it was a boy? In all honesty, I did want Molly Rose back. I wanted it to be the same...a perfect time. In reality I knew it couldn’t be. My heart would always ache for my little girl. But now being blessed with twins, I could not be without my little boys. They are their own identities and I love them immensely and endlessly. Is it asking too much that I could not have them all?” (Jill)

“ We were already ‘trying’ when Lewis died, so for us there was no decision. Harris arrived nine days before the first anniversary of Lewis’s death. Anticipating what might happen when he was born was far worse than his actual arrival. I’m glad he was born before the day – he helped us see that there is still a future. I thought that some of the huge black hole might disappear with the arrival of a new baby, but it didn’t. Lewis’ death and Harris’ birth remain completely separate issues. The one does not affect the other – but we have another precious child to pour our love into.” (Kath)





You may find it helpful to read “Another baby? The decision is yours” which was written by parents, and is available from your local SIDS organisation.

For some families, having another baby is not possible, and this adds to their sense of loss.

“ In my case I underwent an emergency hysterectomy and therefore the possibility of having another child was taken out of our hands. In some ways I feel that the hysterectomy has been harder to accept than Hemani’s death. I make impossible deals – if I can have my uterus back I won’t grieve any more. I see how new babies can help to heal other grieving families and desperately want that small amount of comfort too. Having the decision to have another baby taken away from us has left me feeling powerless and given me even more ‘what if’s’ that can never be answered.” (Megan)

When people ask...

When people ask, “How many children do you have?” you may choose to always mention your child who has died, or depending on the circumstances, you might decide not to.

“ When people ask me how many children do I have, I have to acknowledge Samuel. Whenever I’m asked now, I say “I’ve had three and one has died”. It’s important for me to acknowledge him.: (Jenny)

“ People say “Do you have kids?” I still grapple with it. I used to say “Yes, I have two daughters and I had a son who died”. Now I choose who I tell, because some people don’t know how to handle it.” (Peter J)

“ People ask all sorts of questions that can really throw you, “How are you feeling?”. “Do you have children?”. It took me a while to realise that I didn’t have to provide the truth, the whole truth on every occasion – life isn’t a courtroom. Sometimes if someone asked how I was feeling when I was feeling really rotten I’d just say, “Fine thanks” because I didn’t want to talk about it. It was the same with people asking whether I had children; I realised I could choose what to answer depending on whether I felt like explaining or not But sometimes I would feel that this was denying the importance of James to who we are, and increasingly I do feel like explaining about the fact that we had been parents and what had happened to James.” (Jack)

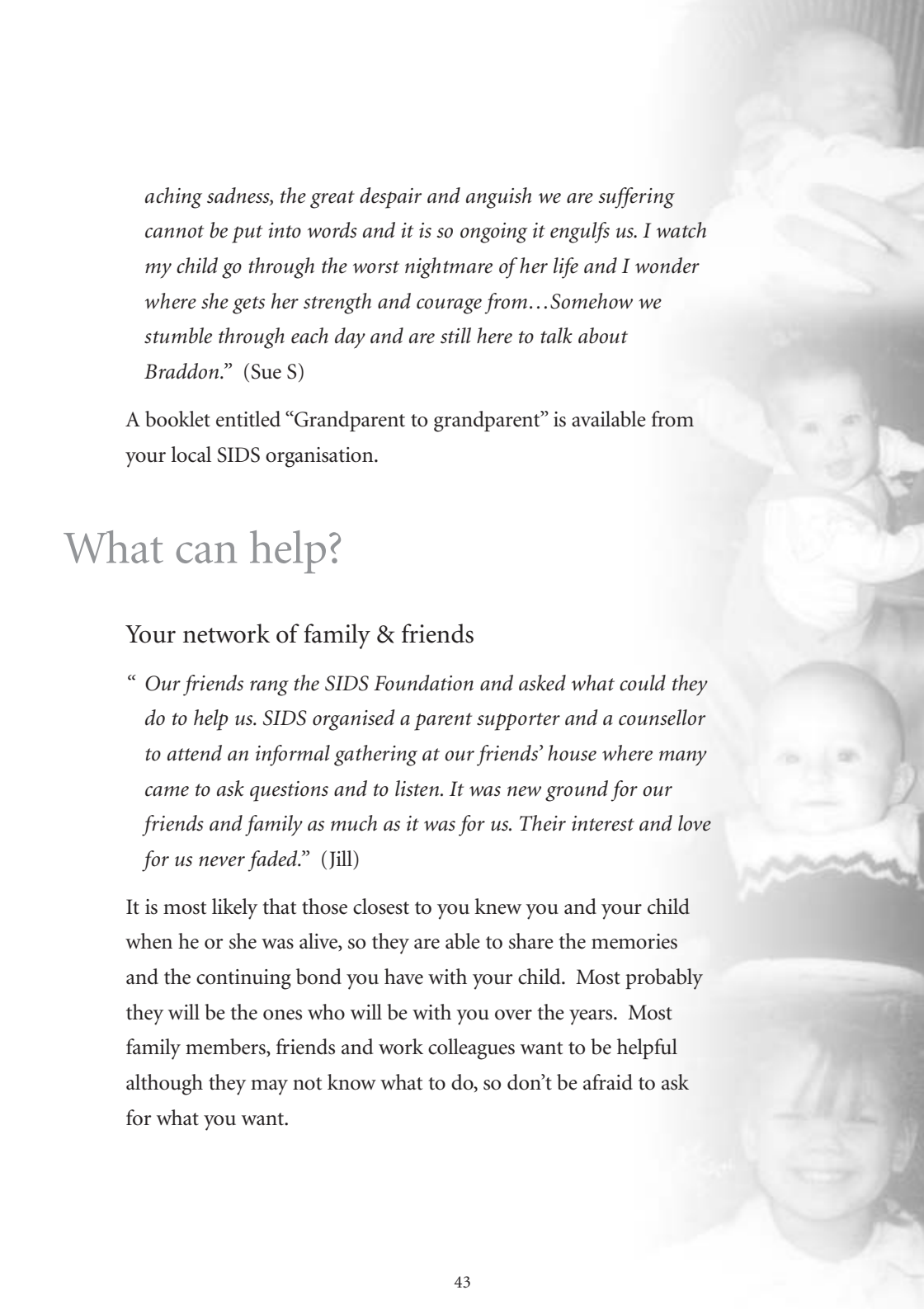
Grandparents’ grief

Grandparents suffer the death of a loved grandchild and also the grief of seeing your sorrow and pain. Often they feel helpless and frustrated by their inability to comfort and protect their own child from their pain and distress. They, like you, need support and care from those around them.

“ My mother said that, unlike when I was young, she couldn’t hold me, or put a bandaid on to ‘make it better’. She felt helpless because there was nothing she could do to ease my pain. I love the way mum and dad talk about Henry as their grandson, and continue to do things for him. My parents grieve for their grandson.” (Sue W)

“ My grandson, Braddon was taken from us by murder. Nothing can prepare you for a loss like ours. The horror, the disbelief, the





aching sadness, the great despair and anguish we are suffering cannot be put into words and it is so ongoing it engulfs us. I watch my child go through the worst nightmare of her life and I wonder where she gets her strength and courage from... Somehow we stumble through each day and are still here to talk about Braddon.” (Sue S)

A booklet entitled “Grandparent to grandparent” is available from your local SIDS organisation.

What can help?

Your network of family & friends

“ Our friends rang the SIDS Foundation and asked what could they do to help us. SIDS organised a parent supporter and a counsellor to attend an informal gathering at our friends’ house where many came to ask questions and to listen. It was new ground for our friends and family as much as it was for us. Their interest and love for us never faded.” (Jill)

It is most likely that those closest to you knew you and your child when he or she was alive, so they are able to share the memories and the continuing bond you have with your child. Most probably they will be the ones who will be with you over the years. Most family members, friends and work colleagues want to be helpful although they may not know what to do, so don't be afraid to ask for what you want.

“ The people that matter most in the world are your family. Blood is thicker than everything. Ultimately, it’ll be your family and friends that really matter.” (Lesley)

“ You take for granted your family and friends until something like this happens, and they are all there for you, arms open wide, shoulders to cry on. Our family and friends have been great.”
(Leeanne)

“ I kept going to everything we were invited to. I think the alternative of withdrawing would have been harder on me.”
(Jenny)

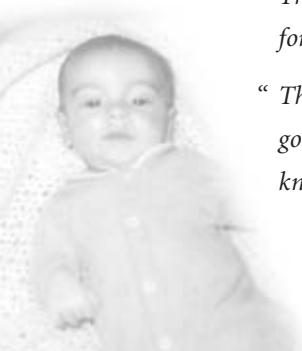
” We could have easily rolled up in a ball and stayed at home and not gone out. Instead we went back to work fairly soon after Rachel’s death, and we feel that was the best thing we could have done.” (Leeanne)

Helpful people

It is important to find someone who will walk beside you through your grief, someone who won’t try to fix it, but just be there. No-one can fix it, but the best help you can get is to have someone who really cares, and will listen to you. Find a good listener, someone who will allow you to tell your story as often as you need too.

“ They listen without offering any solution. They don’t try to fix it for you.” (Anthony)

“ The truest and most precious people are the ones who just keep going with you into the horizon. I may not see them a lot, but I know they are there, and that in another ten years, I can mention



Samuel's name and I can say "I'm having a bad day", and I don't have to say why. Other people don't have the endurance; they can't do it any more, and they fall away." (Jenny)

"I couldn't bear the thought of Lewis disappearing from our lives. I talk about him and say his name at every opportunity. I admire the people who are not frightened to speak his name, or remember..." (Kath)

*"Some of the things I found most helpful were:
When people I came into contact with were willing to acknowledge Saffron's death to me;
People tuning into where I was at emotionally were more helpful to have around me than people who just felt the need to be with me;
People who were able to follow my lead and not assume to know how I felt;
People willing to just sit and listen to me were often the most supportive people to be with, particularly in the early stages of the grieving process." (Lisa M)*

"It's very difficult for people. I give people credit for actually saying something instead of nothing. Just to say or write to me and say "I'm thinking of you" was enough for me." (Susan)

"I loved it when people said they were thinking about us, praying, whatever. I felt like I was being held. All I said was, "Thanks, that means a lot." (Fiona)

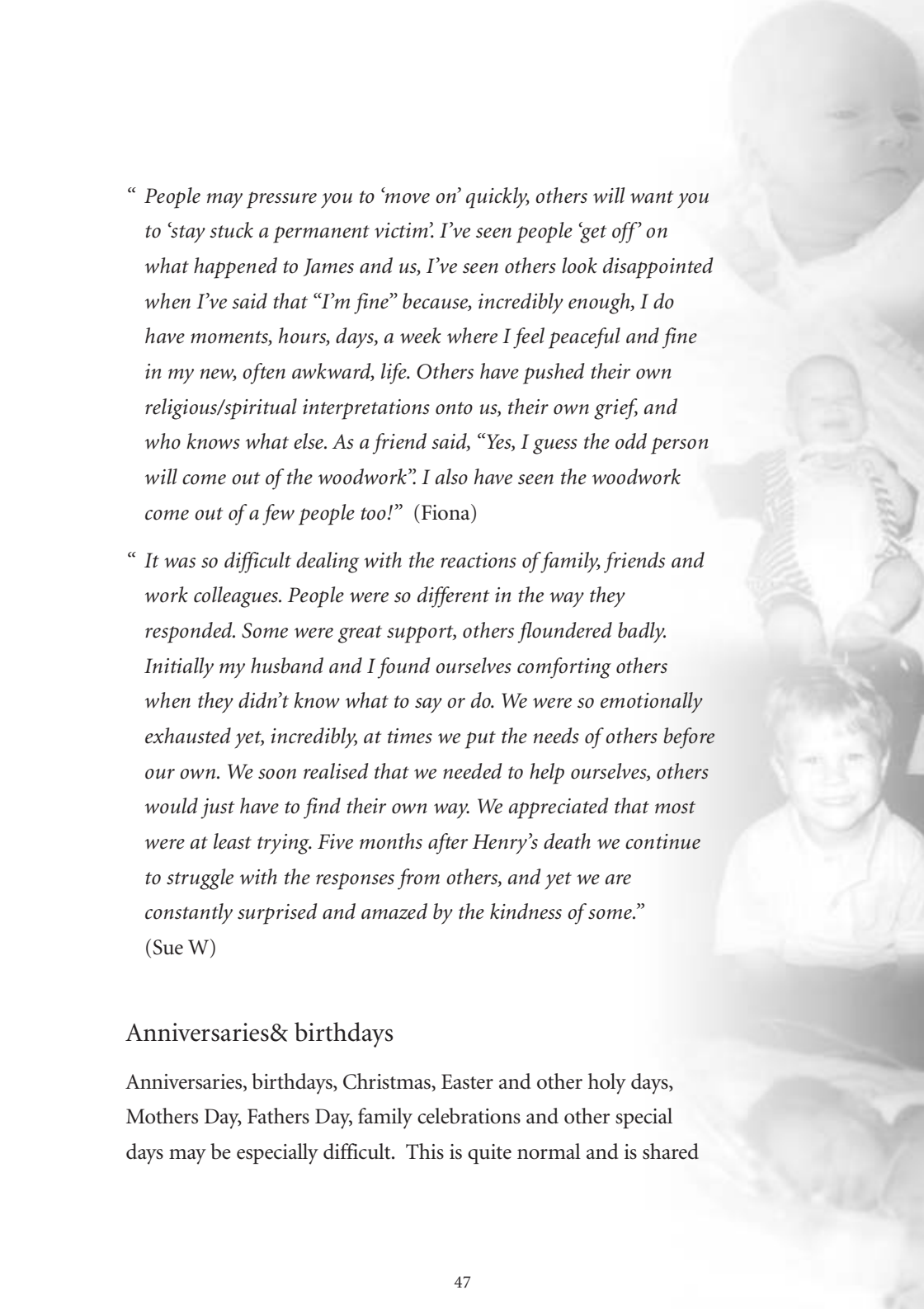
Insensitive comments

Death is a difficult subject and some people do not know how to respond to a person who has had a loved one die. While many of your family, friends, neighbours and work colleagues show compassion and sensitivity and support you, others may 'mean well' but say and do all the wrong things. Some might not know what to say to you and may avoid you. While it is probably a hard thing to do, try not to take offence, but realise that this comes from their lack of understanding and is not necessarily an indication that they don't care.

“ People would see me in the street and ask about my baby. I'd have to tell them he had died. They'd be shocked and embarrassed as they struggled with their responses. Words of comfort brought tears but the sharing was worth the difficulty. Words may seem inadequate, but acknowledgement is so important to a grieving person. Sometimes people talk a lot about other things to protect themselves. It takes courage to break through and broach the pain, to speak the name of the one who is foremost in the mind.” (Erica)

“ Saffron was a twin. Some of the most hurtful comments we received were from people who felt the need to say something, therefore it was often a comment they hadn't put a lot of thought into; such as: “At least you still have a baby”; “How would you have coped with two babies anyway”; and “At least you have a son”. I was heart-broken every time somebody made such a comment. Finding ways to cope with such comments still eludes me today.” (Lisa M)



A faded, grayscale background image showing a baby in the upper right and a young child in the lower right. The baby is looking slightly to the side, and the child is smiling.

“ People may pressure you to ‘move on’ quickly, others will want you to ‘stay stuck a permanent victim’. I’ve seen people ‘get off’ on what happened to James and us, I’ve seen others look disappointed when I’ve said that “I’m fine” because, incredibly enough, I do have moments, hours, days, a week where I feel peaceful and fine in my new, often awkward, life. Others have pushed their own religious/spiritual interpretations onto us, their own grief, and who knows what else. As a friend said, “Yes, I guess the odd person will come out of the woodwork”. I also have seen the woodwork come out of a few people too!” (Fiona)

“ It was so difficult dealing with the reactions of family, friends and work colleagues. People were so different in the way they responded. Some were great support, others floundered badly. Initially my husband and I found ourselves comforting others when they didn’t know what to say or do. We were so emotionally exhausted yet, incredibly, at times we put the needs of others before our own. We soon realised that we needed to help ourselves, others would just have to find their own way. We appreciated that most were at least trying. Five months after Henry’s death we continue to struggle with the responses from others, and yet we are constantly surprised and amazed by the kindness of some.”
(Sue W)

Anniversaries& birthdays

Anniversaries, birthdays, Christmas, Easter and other holy days, Mothers Day, Fathers Day, family celebrations and other special days may be especially difficult. This is quite normal and is shared

by other families that have experienced the death of a child. You may find that the lead-up to these days can be worse than the day itself.

There are no rules about how (or even whether) to mark anniversaries, birthdays and special days. Some families visit the grave with balloons, some write a poem, add a special plant to the garden, light a candle, make a special Christmas decoration, or get-together with family members and browse through a photo album. Whatever you decide, do not expect too much of yourself, but do whatever is helpful and meaningful for you.

“ I cried all day on the first and second years. Last year on the fourth birthday, we went out for lunch and it was a nice day.” (Jenny)

“ Those first few years it just hurt too much. I was so sad when I thought about Brendan’s birthday. A few years later I wanted to get the photos out because I wanted to feel; I wanted to remember. Now I don’t have that pain. Now, when I think about his birthday, I think of it quite warmly and affectionately. I will always regret that fact that he’s not here, but it doesn’t have the same shocking sadness that it did then. After twelve years I still look for a way to celebrate Brendan’s birthday – a way that will make me feel happy and at peace.” (Lesley)

“ On birthdays, I tend now to confide in someone I know at work who has had a child die. There is a special bond between us. We talk for hours about our losses. So I go and just say to someone like that, look, it’s Brendan’s birthday. And a letter turns up every year from a cousin’s wife, and a card saying “We’re thinking of you Brendan and the girls”. It’s just nice – she hasn’t forgotten. I love getting the letter.” (Peter J)

“ We’re approaching the first Christmas and it’s going to be a very difficult time, missing Candice. I’ll have my young niece around and my sister-in-law has two kids. Being around the little ones will be difficult. Candice will be greatly missed.” (Lara)

“ The first Christmas was unbearable. I wanted to shut myself away. Sam was our only child at that time, and there seemed to be no point to Christmas. Now, we celebrate Christmas because we have Lucy and James. While one part of me wants it to be a happy family celebration, the other part of me is sad and reflective because Sam is not here. We all feel Sam is close when we place his special decorations on the tree.” (Wendy)

Creating memories

Over time, you may find that creating something in your child’s memory is a helpful way of continuing the loving bond you have with your child. It provides a tangible opportunity to recognise the importance of your child’s life, often when others are encouraging you to move on.

Some things that parents and others have done include: writing a journal, creating an album of photographs and mementoes, making a memory box, carving the headstone, writing poetry, stitching a special sampler, pressing flowers from the funeral, creating or building a special place in the garden, expressing feelings through drawing or painting, having a sketch drawn of their child, writing a book, writing a poem or letter to their child, and having an item of jewelry engraved with their child’s name.

“ I started to stitch a sampler of hearts within a couple of weeks of losing Lewis. Having something to do ‘for’ Lewis was necessary to fill some of the long, long, hours that he would have otherwise occupied.” (Kath)

“ For the first three months following Henry’s death I worked on a booklet about his life and death. I do feel that writing and illustrating the booklet assisted in my healing.” (Sue W)

You may take comfort in your beliefs

If you have religious beliefs you may find your faith comforting. On the other hand, you might find that your faith has been shaken. You may find it helpful to speak with someone who shares your belief or faith.

“ Bad things happen to good people”. Being Christian, my feeling was that Samuel was with God but I didn’t believe that God had taken him. I just believe that bad things happen – that we don’t do anything to deserve them.” (Jenny)

“ I was brought up a Catholic but I do not have much belief. I do take some vague comfort and like to think of my dad and my son together.” (Peter J)

Other bereaved parents

Many parents find it very helpful to speak with other parents whose children have died.

Bereaved parents who are trained parent supporters work in partnership with professional counsellors in SIDS organisations



around Australia. Because of their own experiences, parent supporters have a special understanding of what you may be going through. You might find it very helpful to speak with a parent supporter at some stage.

“ When Sam died I experienced the richness of parent support. The parent who supported me sparked a light in the darkest times of my life. She provided me with a hope that I could survive.”
(Wendy)

You might also find that attending a group for parents provides you with invaluable support, and ‘normalises’ what you are thinking and feeling.

“ There is a common bond between parents. Just talking with someone who’s had a child die helps, regardless of the cause.”
(Lesley)

“ I’m comfortable with other bereaved parents. I feel safe and find comfort with them. When you’re with other parents who have had a child die you don’t have to worry about being misunderstood. You have the freedom to say anything; to do anything; to feel anything; to think anything, and know others understand.” (Sue W)

“ Sharing one’s grief lessens the load. The more you share, the lighter the load becomes.” (Glenn)

“ One of the best things that we have done is to be a part of a group because it has given us the opportunity to express ourselves freely. You’re given the freedom to share. It has been good to talk to other people who have been through something similar. Even if their

child has died in very different circumstances, the empathy is there straight away. We have been involved as parent supporters with SIDSvictoria for a number of years. I guess we are trying to make something of our sense of loss by putting back into the organisation which helped us when we found ourselves in a lot of need. Also we want Brendan's life to mean something, and if that's reflected in trying to help a few other people then so be it – that's great.” (Peter J)


If you would like to speak with a parent supporter or attend a group, contact your local SIDS organisation.

Talking with a counsellor

Some parents do not want or need to speak with a counsellor. Others find it helpful to talk with a counsellor who understands grief. There may be things that you can say to a counsellor that you do not feel able to say to someone close to you. You will find counsellors at the SIDS organisation in your state or territory, or you may choose to talk with your doctor, a social worker, psychologist, member of the clergy or another counsellor.

“ People should not be scared to take advantage of counselling. They should not feel they are not good enough because they can't cope. It's OK to say “I need help”. I found it was good to find that outlet – to release that pressure. I'm not ashamed to hold up my hand and ask for help. I talk when I need to, and listen when I want to. I am surviving.” (Sue W)





“ We have had fantastic support from family and friends, but there is something special for me about talking to a good counsellor. In conversations with family and friends, I am always conscious about how they are feeling, whether they are upset by what I am saying, whether I am listening to them enough rather than just unburdening myself. With a counsellor it’s different. It’s still a very personal relationship, but there is a level at which you don’t have to accept the same responsibility for their feelings and reactions.”

(Jack)

Changes over time

Grief after the death of a child takes a long time. It takes a lot of your energy and it is tiring. Some days you will feel you are making progress, and then other days you will be back to ‘square one’. You will find that the first year or so has many painful times, but gradually the acute anguish you experienced soon after your child died, lessens. Although the feelings will be the same, they will diminish in intensity.

“ I surf the waves. Sometimes the waves are dumpers, sometimes smooth. I have to just flow with it.” (Fiona)

“ I feel that we as a family have to keep going on with what we enjoy doing. Sometimes you feel that the wheel of life is turning fine, then you feel empty inside; there is something missing. The wheel has a flat sharp edge that hits you straight in the heart.” (Darren)

“ Sixteen months later I still often have flashbacks to my son’s accident which rise up and nearly choke me. An innocent word here or there can set me off, but I recover more quickly now.”

(Kath)

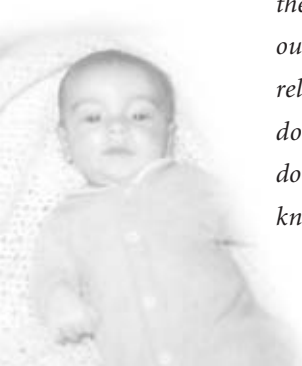
Despite the fact that you may have longed for a break from the pain, you may feel guilty if you find yourself laughing and actually enjoying something. Because as uncomfortable as grief may be, it is a connection with your child, a constant reminder of the love you have for him or her. When the pain lessens, you may fear that that loving connection is breaking. But it isn’t.

“ Sometimes I even allow myself the opportunity to laugh and smile. I have read how people learn to ‘live with their pain’ and must admit that for many months I was unable to grasp this concept. I think I am just now starting to understand what they might be saying.” (Sue W)

A changed outlook

The death of a child is a life-changing event. You may feel ‘out of the norm’ for quite a while. This too is normal, and eventually will pass.

“ All my priorities were re-ordered. For the first time for ages it was the real things that counted. What mattered to us was the loss of our child and all the implications that that had for our relationship and for our surviving daughter – implications for her down the road. I certainly remember going back to work and doing that too quickly and how trifling most things were. You know, people bitching and whingeing about normal things at



work, which to me were totally insignificant, and so it resets your priorities totally. You don't care about any of that. You put on a facade – you go through the motions but it really does alter your priorities for a considerable amount of time. You are off to the side from everyone else for ages. But eventually you're dragged back into the normal realm of things, and I can't put an accurate timeline on when that happened for me.” (Peter J)

“ Initially nothing was important. I remember standing in the driveway waiting for the ambulance, -just bargaining–take the house – take everything else, if you'll only give Samuel back to me. But as time goes on and you go back into society, I'd like to say that all those material things aren't important anymore, but they come back to be. Money is an issue with us now. Those things creep back into your life because they have to – you're living – those priorities have to be there. You've got to have money; you have responsibilities and things at work do get you down. You get back into the swing of life.” (Jenny)

Remembering

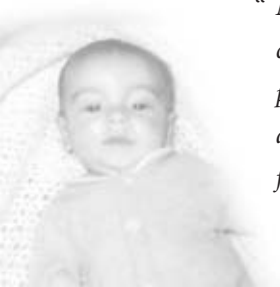
In the future, sadness may still overwhelm you at times, but eventually you will find a way to live on. Many parents find it takes two to three years before they find ease of mind, and a sense of meaning in life again. You will be changed by this experience, you won't be the same person you were before. You will never really 'get over' the death of your child. You will remember and grieve a little for the rest of your life, but in time life will be meaningful again. Your child will always be your child, and the love you have for your

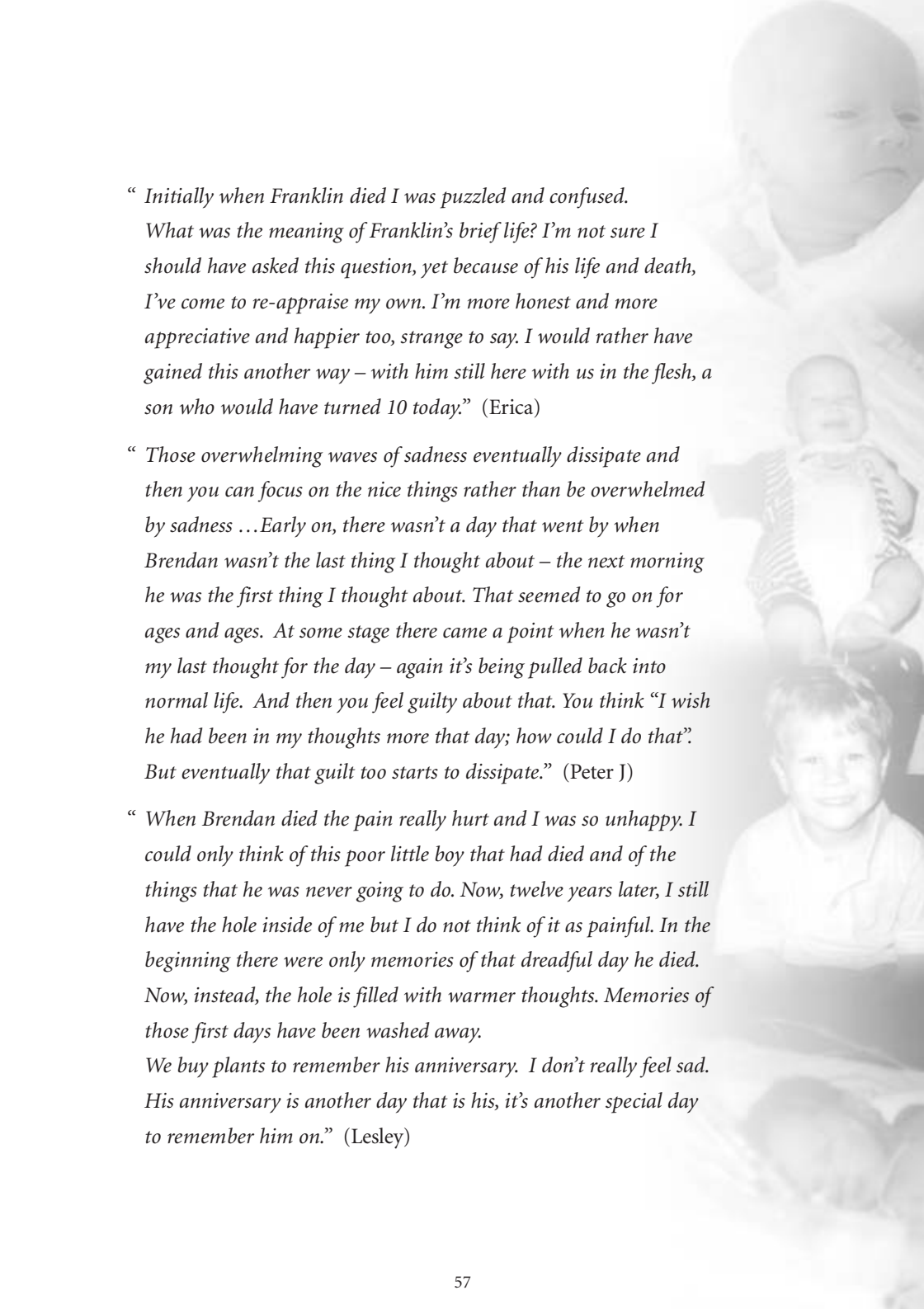
child will ensure that he or she will always be a very special and precious part of your life.

“ Early on, very early on, I knew that to survive and eventually thrive I would have to live from the love that James, Jack and I had, a much more powerful reality, and one that no murder, court case, media exposure could change. My survival as a reasonable human being and my ultimate desire to thrive in a new life means I look after my heart and Jack’s. People who trample that are moved out, delightful beautiful people have moved in since James’ death, a stunning humanity has blossomed. Our son lived a short life, but he lived well. He played hard, he was surrounded by love, he knew no fear, and he loved. More than many experience in a longer lifetime. When Charlie Parker (Bird) a famous jazz musician died, people graffitied American cities with ‘Bird Lives’. I wanted to spray paint our town ‘James Lives’. And in many ways he does – even though my body and heart ache and, in a way, always will.” (Fiona)

“ Nearly four years later, and tears still fall. Memories still flow daily of Molly Rose’s sweet little life...of our time together. And I don’t want that to change. I have to remember. Life does go on and day by day circumstances change. I have become stronger. Although my dreams were shattered I am now able to focus on other things. But our time together was a very important and special part of my life.” (Jill)

“ My son died five years ago at the age of eight months. It certainly changed my life and my way of looking at things. I am a very positive person now and before I tended to be pessimistic. I learned about grief, about human nature, and about what friends and family mean to me, whilst I was grieving.” (Susan)





“Initially when Franklin died I was puzzled and confused. What was the meaning of Franklin’s brief life? I’m not sure I should have asked this question, yet because of his life and death, I’ve come to re-appraise my own. I’m more honest and more appreciative and happier too, strange to say. I would rather have gained this another way – with him still here with us in the flesh, a son who would have turned 10 today.” (Erica)

“Those overwhelming waves of sadness eventually dissipate and then you can focus on the nice things rather than be overwhelmed by sadness ...Early on, there wasn’t a day that went by when Brendan wasn’t the last thing I thought about – the next morning he was the first thing I thought about. That seemed to go on for ages and ages. At some stage there came a point when he wasn’t my last thought for the day – again it’s being pulled back into normal life. And then you feel guilty about that. You think “I wish he had been in my thoughts more that day; how could I do that”. But eventually that guilt too starts to dissipate.” (Peter J)

“When Brendan died the pain really hurt and I was so unhappy. I could only think of this poor little boy that had died and of the things that he was never going to do. Now, twelve years later, I still have the hole inside of me but I do not think of it as painful. In the beginning there were only memories of that dreadful day he died. Now, instead, the hole is filled with warmer thoughts. Memories of those first days have been washed away. We buy plants to remember his anniversary. I don’t really feel sad. His anniversary is another day that is his, it’s another special day to remember him on.” (Lesley)

“ I remember the raw pain, the shock, the feeling of hopelessness, confusion, anger and sense of being a total failure. I remember it all. It is a black void that will be with me for as long as I live. I don't think of my beautiful son Jack every day. I have reached a level where it's just part of me. The pain is still there and I could tap into it any time, but I choose not too. My outlook on life has changed. I am definitely more positive now. I also have different values. I wanted Jack's death not to be in vain. I wanted it to mean something and, I believe, over the years it has, and will continue to do so.” (Glenn)

“ Jason died at 6 months and 3 weeks. He would be 31 years old now. I am now the grandmother/step grandmother to twelve little Australians. Thank God they are all progressing well – fit and healthy. I am a large woman and appear outwardly strong to most of the people I meet. Deep down though, I'm just a human being who happens to be a mother who every so often 'gets her buttons pushed' for no apparent reason and grieves for her lost child. Perhaps this is what I want people to know – the pain and hurt never goes away – it just becomes more bearable over the years.” (Josephine)

Acknowledgments

We would like to sincerely thank the following parents for their contributions to this booklet:

- Josephine Gwynne (Jason – 22.2.68 - 12.9.68)
Wendy Claridge (Sam – 2.12.85 - 9.3.86)
Glenn Nicholson (Jonathan [Jack] – 10.9.87 - 5.10.87)
Lesley and Peter Jones (Brendan – 1.12.87 - 28.4.88)
Erica Kurec (Franklin – 18.1.89 - 21.7.89)
Susan Williams (Phillip – 26.10.92 - 5.7.93)
Jenny Robinson (Samuel – 29.6.94 - 1.10.94)
Chris Schilling (Tahlia – 9.12.94 - 9.12.94)
Jill and Ian Green (Molly Rose – 1.8.95 - 27.4.96)
Debbie Myers (Tessa – 6.1.84 - 16.5.96)
Bridget Plane (Stephanie – 4.8.96 - 29.9.97)
Elaine Duggan (Paris - 20.7.96 - 8.3.98)
Megan Sarson-Lawrence (Hemani – 8.5.98 - 18.5.98)
Narelle Gregory (Tara – 24.3.96 - 8.6.98)
Lisa Mennen (Saffron – 1.6.98 - 1.7.98)
Karen Ollis (Jessica – 18.1.94 - 14.7.98)
Kath Mitilineos (Lewis – 15.1.97 - 19.7.98)
Sue Wilkinson and Anthony Faure (Henry – 3.9.98 - 16.9.98)
Therese Considine (Julian – 21.3.94 - 24.10.98)
Leeanne and Darren Weadley (Rachel – 8.12.97 - 14.11.98)
Melissa Ryan (Danielle – 31.7.94 - 1.2.99)
Fiona Strahan and Jack Gilding (James – 7.11.97 - 7.2.99)
Adele Eslick (Martin – 11.8.98 - 9.2.99)
Peter Moore (Daniel - 7.5.91 - 7.4.99)
Lara Burnell – (Candice – 22.4.99 - 29.5.99)
Lisa Park and Sue Scott – (Braddon – 17.11.93 - 12.7.99)
Tracy Young – (Ethan – 4.10.99 - 7.10.99)

Publications available from your local SIDS and Kids office

Choices in arranging a child's funeral

For SIDS families: Some answers to your questions

Grandparent to grandparent

To family and friends – You can make a difference

Things about Zac my baby brother

Another baby? The decision is yours

Other publications and videos are available for parents, children, health professionals and others affected by the sudden and unexpected death of a child.



“Copyright of this publication is vested in SIDS and Kids. We permit free copying of all or part of this booklet for the purposes of disseminating the information contained in it, without cost, for the public good, provided that its source is acknowledged. For any other purpose, for example, for commercial or profit-making purposes, we assert all our rights as owners of copyright under the Copyright Act (Cth) 1968, as amended and we do not give free or unlimited copying access for commercial or profit-making purposes.”

SIDS and Kids Organisations

For more information, further reading materials or if you would like to talk to someone please contact the SIDS and Kids office in your area on 1300 308 307 or visit the SIDS and Kids website on www.sidsandkids.org

Co-ordination and compilation by Vivienne Bateman (SIDS and Kids Victoria).

With special thanks to Anne Giljohann (SIDS and Kids Victoria) for her commitment and support.

Thanks to Alicia Patterson of Education Image Pty Ltd. for her thoughtful editing.

Thanks to George Patterson Bates for the cover design.

This publication has been made possible by the generous contribution of Kaarene Fitzgerald AC, following the presentation to her of the National 1999 Avon & Woman's Day Spirit of Achievement Award.

Reprinted December 2003.



sids^{and}kids